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Health & Human Services

Interim Committee

Presentation


"Funding Services for Persons with a Disability"

June 17, 2009

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Why Do We Provide Services?

We serve people with disabilities in the state of Utah because we are legally obligated to do so under state and federal law.

If Utah does not serve people with disabilities -- and their situation worsens so that they need institutional care -- federal Medicaid law requires Utahns to pay for that institutional care (where costs could be above \$60,000 per year per person). Therefore, the legislature designed a program to keep people from getting worse. This was done in order to save taxpayer money. If we serve people in their own homes with supports, such as a person coming in and helping them bathe, dress, eat and go to work, then the costs are much lower and the person stays at home.

We are required by Utah law 62A-5-102 to “plan and deliver an appropriate array of services and supports to persons with disabilities and their families in this state.” We determine who get services based on the 1) severity of the disability, 2) the urgency of their need, 3) ability of family to provide care, 4) length of time person has waited. (UCA 62A-5-102 (4)).

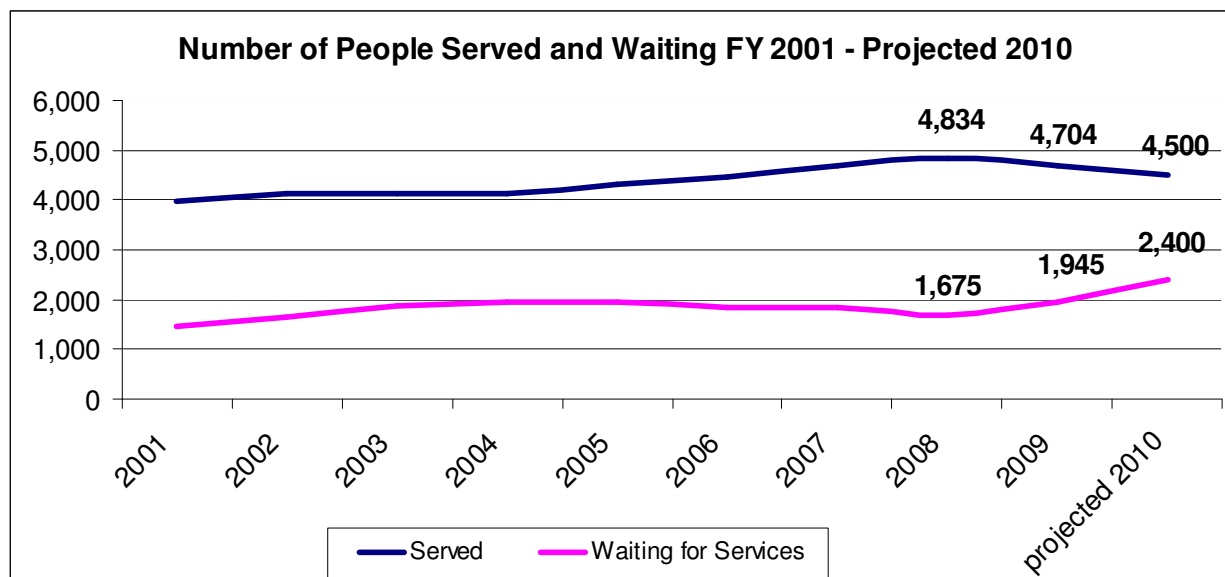
State law sets forth our policy direction that we are to provide services “in the least restrictive and most enabling environment” and “enable reasonable personal choice in selecting services and support.” (UCA 62A-5-102 (6)).

State law sets forth the following principles shall be used as the basis for supporting families who care for family members with disabilities: 1) children should reside in a family like environment, 2) families should receive the support they need to care for their children at home and 3) services should complement and support the families and their specific needs (UCA 62A-5-403(2)).

Past Utah policy has emphasized in-home placement rather than placement in a facility. Indeed, Utah's facilities for people with disabilities operate at near 100% capacity. If Utah wants to shift back to a more institution-based approach, new facilities would have to be built. Currently, the Division serves about 4500 people who are eligible for institutional care. Utah would need about 90 new facilities (assuming each could serve 50 people) to meet the need.

How Many are Waiting for Services?

The number of people waiting for services is increasing over the past year. The waiting list grows when the amount of funding appropriated by the Legislature to bring people off the waiting list is not enough to offset growth in the number of people waiting. People who die, move out of state, enter an institution or who fail to respond to the annual waiting list survey are removed from the waiting list. In addition to the annual survey, waiting list workers make contact with families on the waiting list at least once a year to check how things are going and to record changes in the family's status on the waiting list. In FY 2008, there were 1,675 Utahns waiting for services and 4,834 Utahns who received services. As of May 2009, there are 1,945 Utahns on the Division of Services for People with Disabilities' waiting list and only 4,704 people receiving services. The number waiting for services is expected to grow by about 455 people in FY 2010 while the number receiving services is expected to drop by 200 people due to attrition.



In addition, it is estimated that there are thousands of Utahns with disabilities who have not applied for services and who therefore do not receive any government disability services. Every month approximately 90 Utahns across the state apply to the Division for services. Of those who apply, only 42 percent are found to meet eligibility requirements and have their name placed on the Division's waiting list. Thus, about 625 of the approximately 1,080 people who apply for services each year are found to be ineligible or decide not to follow through with eligibility determination after learning more about eligibility requirements.

What Does a Family Who is Waiting for Services Look Like?

James is a well-educated father of four who has a good job as a general contractor; his wife is a teacher. They have insurance thanks to her job. They pay their bills and taxes. They live in a nice Utah neighborhood and have a good group of supportive family and neighbors. Their oldest son has autism and is developmentally delayed. The family has cared for him by themselves for more than thirteen years, but in adolescence he has become more challenging, violent and disruptive. He is physically larger than his mom and siblings, he threatens schoolmates, and he needs constant supervision. The family has not gone out to eat, to church or even to the grocery store together for many years – all of their activities center around their disabled son. They have been on the waiting list for years and have received no services. As their son's behavior puts their family at risk, they are asking for a small amount of help – maybe a respite worker to come in a few hours a week and back the parents up. This would cost the state about \$10,000 per year. Insurance does not cover it for this family. Their family and friends will not do it – they are exhausted and burned out.

Since September, entry to any services has been frozen, and we must tell the family we can do nothing for them. They call their legislators and so we want you to know the situation. There is no money for these services and there will not be in the near future. The cuts we took in the last few months have reduced the number of staff that we have available to talk to the family and explain things to them. We are closing offices and laying off workers.

James' family is not unusual. We get calls from these Utah families weekly and the story is the same.

Another two examples: Annie is a 15-year-old girl with extensive behavioral issues as a result of severe intellectual disabilities. She was being served by a private company that specializes in helping young children. They can no longer serve her because of physical assaults against staff and other children, self-injury, and sexual acting out. Her single mother is her family's sole support. The mom cannot handle her behaviors (Annie has attacked her many times), and no intermediate care facility is willing to take her. Mom doesn't want to relinquish custody to the state, but she is considering this because she feels it is her only option.

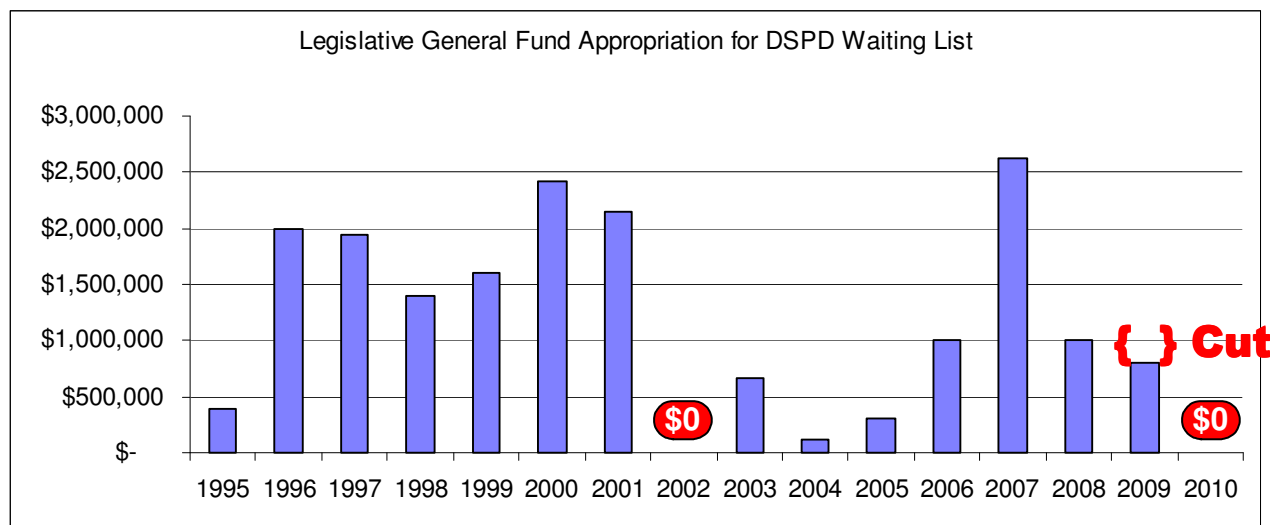
Jane is a 50-year-old person with developmental disabilities whose elderly parents can no longer care for her. They have done it by themselves with no services for 50 years. Now the father – who had hip surgery - is caring for the mother - who has dementia. They have their own home, and they have insurance, but there is no one to watch Jane all day every day as the parents' health fails. They call their legislators and want to know what can be done.

For these families, they ask me “Does my son have to hurt himself or someone else just to get services?” “Do I have to abandon my daughter to the state?” “Do you have to wait until Jane's parents die before Jane can get any supports?”

The answer to that is yes.

How Much Funding Has Been Appropriated?

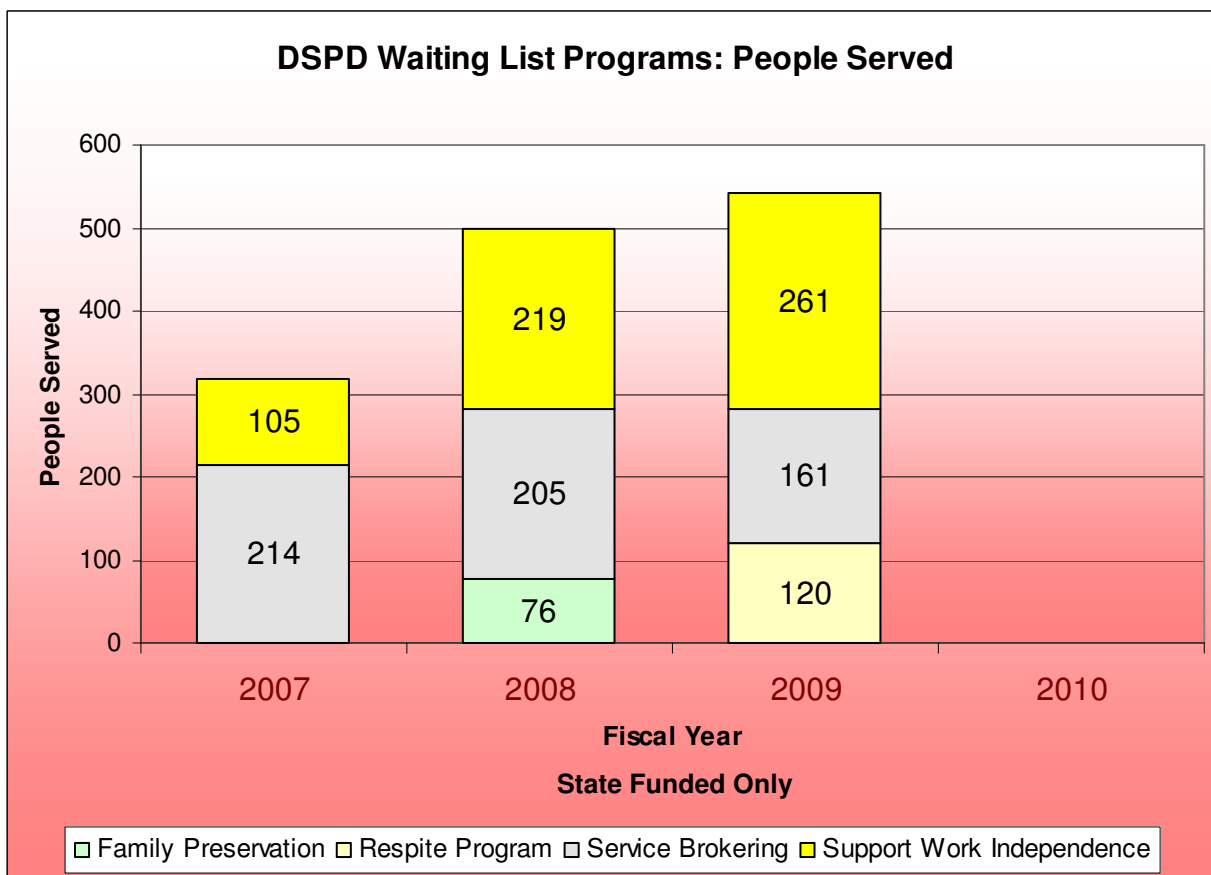
In past years, about half of the new funding allocated by the Legislature was targeted for the waiting list and went to bring new people into services off the waiting list. The remainder went to cover provider increases, losses in the Federal Medical Assistance Percentage (FMAP) rate, or mandated service increases for people already in services. The \$1.1 million allocated in FY 2009 to bring people off the waiting list was reduced down to \$800,000 at the September 2008 Special Session.



From March to June 2009, the Division has experienced a strong increase in the number of people requesting emergency services due to a crisis, with 79 people beginning services due to a crisis during this time period. In comparison, during the same time period last year only 37 people received emergency funding to begin services. A similar increase in requests for emergency funding was also experienced from FY 2002 – FY 2005 when very little funding was available to provide services for people waiting. Unfortunately, when the family deteriorates into crisis and the person has to be removed and placed in residential supports it costs \$50,000 or more per year as the natural supports that were provided by the family are replaced with paid 24-hour supports. Conversely, when funding is available and can be used to maintain the supervision and support usually given by the family, service costs average about \$3,500 per year.

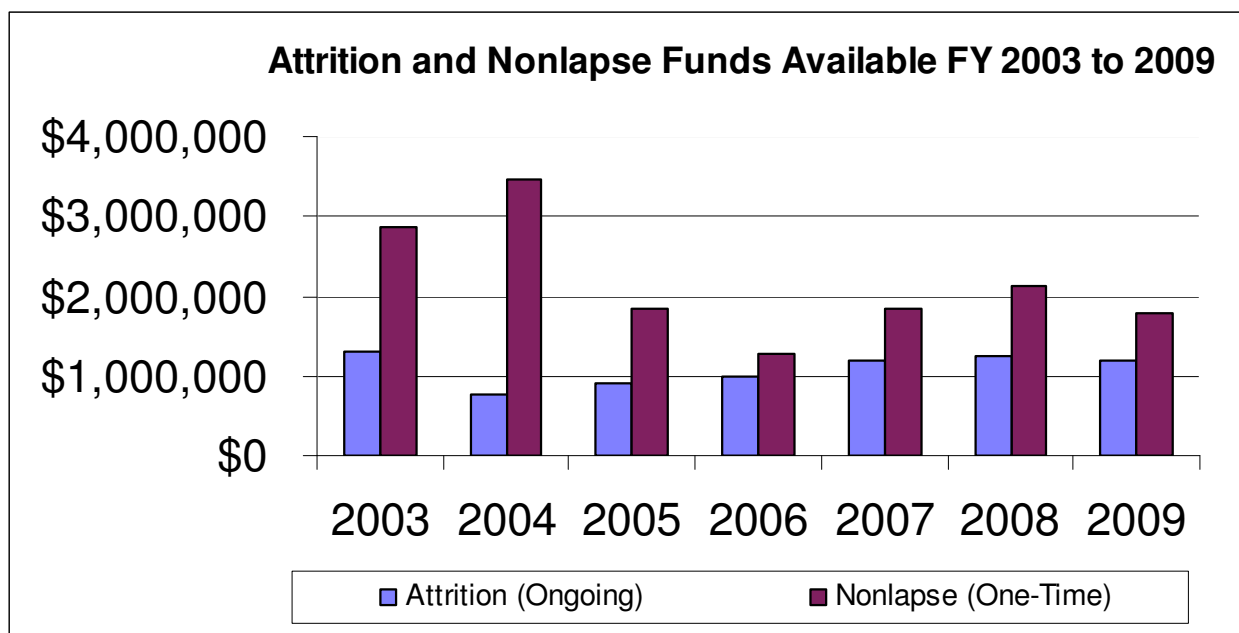
What Do We Do for People While They are Waiting?

In order to provide some care to people whose conditions are worsening while they wait for services, the Division had been providing temporary one-time early interventions to families. These are General Fund only and not usually federally matched. For example, individuals with severe disabilities waiting for ongoing services who cannot read, write or ask for help on their own without supervision received one-time, temporary services like transportation and assistance to get food from the food bank, to go grocery shopping, help to apply for food stamps, assistance paying for utilities, applying for housing assistance, applying for social security benefits, and help to find and keep a job, parents with children who hit and bite their parents and siblings due to their disability received special training on how to reduce these difficult behavioral problems and family stress so their family can avoid breaking up, and families with the most critical need for services received limited respite services. All of these temporary, one-time services that had been provide to those who were waiting for services on the waiting list were frozen in the September 2008 Special Session and will be discontinued due to budget cuts on July 1, 2009. Over 500 people who had received these services will no longer be able to get basic stabilizing services while they wait. The average cost of these services was less than \$1,000 per person in FY 2009.



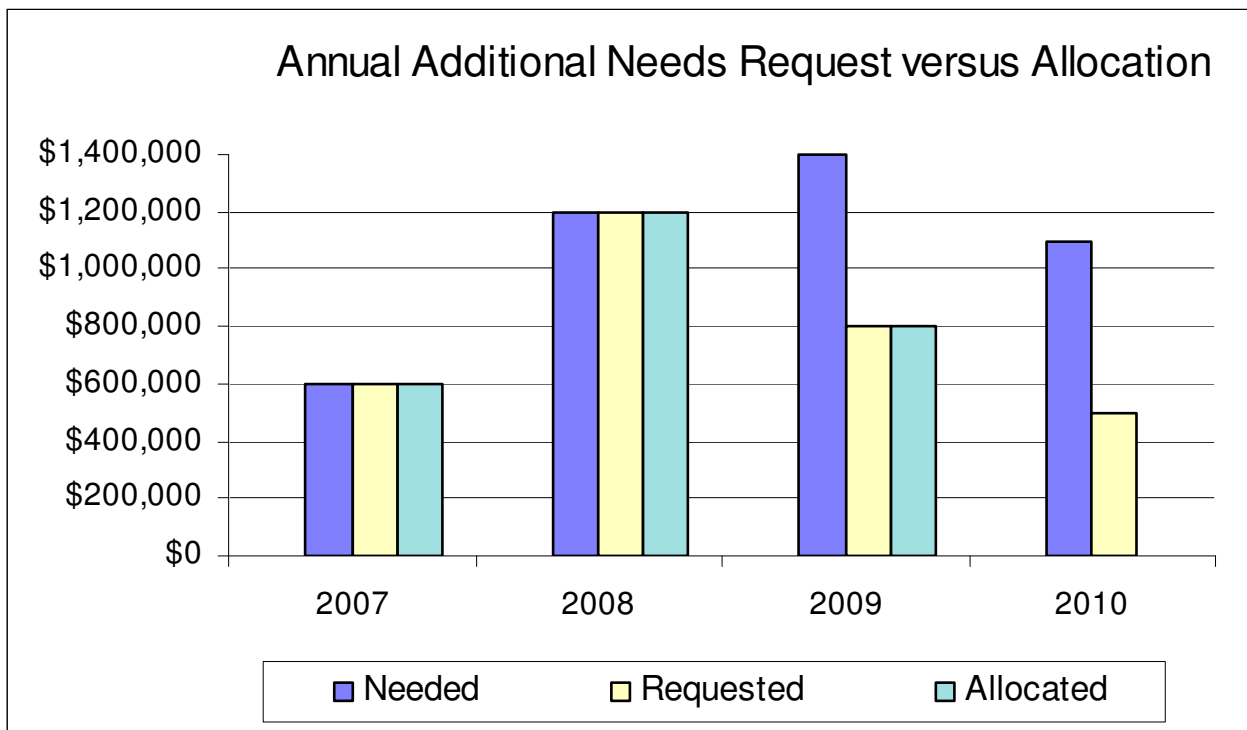
How Do We Spend the Money from Natural Attrition or Nonlapsing?

Around five percent of the total number of people receiving services exit services each year. This is due to a variety of reasons including moving out of state, moving into an institution, death or being found to no longer be eligible for services. The savings this generates is termed “attrition” and creates both one-time and ongoing savings. In addition, “non-lapsing” funds, funds unspent in the current year, are carried forward by the Division and used to cover one-time expenditures in the next budget year. Due to budget cuts the amount of one-time money available for use during the year is quickly decreasing and is expected to run out in FY 2010.



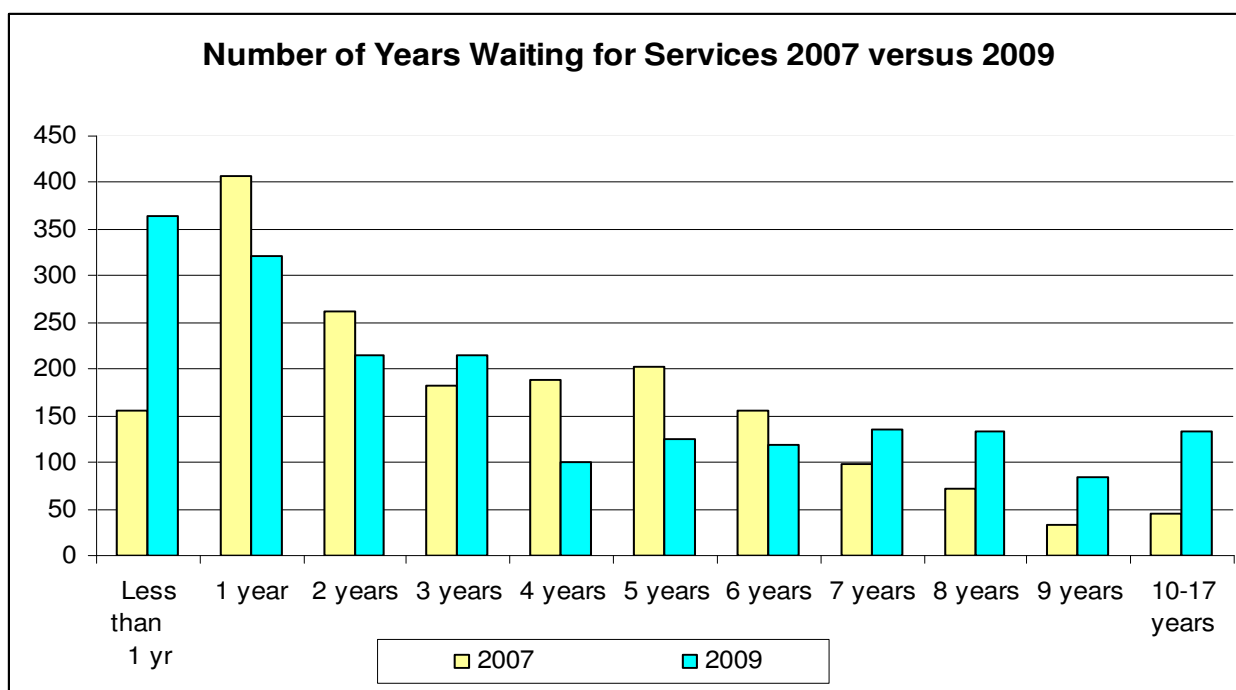
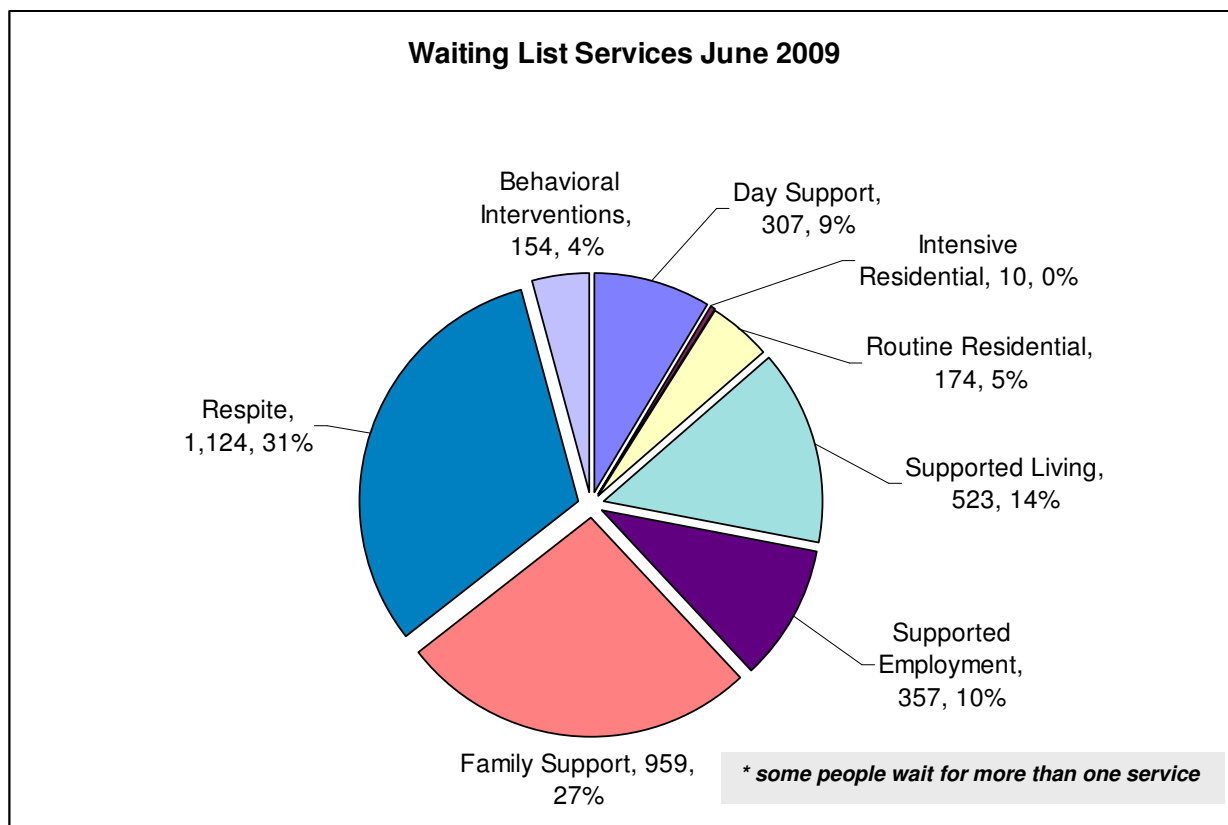
Over the past seven years, the Division has carefully tracked the attrition and non-lapse funds and has used these funds to cover the costs of children aging out of Child and Family Services (DCFS), emergency services and on occasion the cost of part of the mandated service increases and the cost of bringing people off the waiting list before the beginning of the fiscal year. Taken all together covering age outs, emergencies, mandated service increases and early entry into services costs around \$2.2 million per year. The Division reduces its requests for mandated needs funding from the Legislature each year by what it expects to be able to cover with the ongoing and one-time attrition and non-lapse funds (see next page for more detail). For example, the Division reduced its FY 2009 and FY 2010 funding request for mandated needs by \$600,000 because of estimates that \$600,000 in ongoing attrition savings could be put toward additional mandated needs during those years.

How Much Do Legally Mandated Additional Needs Cost Each Year?



Federal law requires us to pay more for people whose condition worsens while they are in our services. Each year since FY 2007, around five percent of those receiving services have experienced a significant change in their life or health requiring more intensive services. Examples of significant life changes include the loss of a caregiver, a health or behavioral crisis, or graduation from school. Loss of a caregiver may require placement in a residential program, loss of school services may require the person's mother or father to quit his or her job to stay home with their son or daughter or to seek funding for day or employment services. Between FY 2007 and FY 2009, the cost to provide additional services ranged from \$600,000 to \$1.4 million in State General funds per year. These services are mandated by Federal law. It is estimated that in FY 2010, meeting mandated additional needs will cost \$1.1 million in State General funds. The Division requested \$500,000 from the Legislature to meet these needs and planned to take care of the balance or \$600,000 with attrition savings. The Legislature did not fund this request, thus over \$100 million in Federal Medicaid funding for Waiver services is in jeopardy if the Division cannot pay for mandated additional needs.

What Services are Utahns Waiting for?



Why Can't the Family Just Take Care of Their Own Needs Within Their Neighborhood?

We would all like to believe that extended family, neighbors or church members would step in. In many cases they already have. They have been involved with these families for years and have done their part and then some. These people with disabilities only qualify for the State waiting list after every other option in their life has been exhausted.

We carefully screen them for need and urgency. If their family is intact and able to care for them they are not found "eligible" to receive funding.

Waiting list allocations are given to people waiting for services with the greatest need. People waiting for services are rank ordered by criticality based on the severity of disability, the caregiver ability to take care of the person and the length of time spent waiting for services. The criteria applied to assign each person a rank on the waiting list in comparison to other Utahns who are also waiting includes:

Severity of a Person's Disability

- Must require frequent supervision
- Must require intense supervision
- Must require supervision due to multiple intense/severe problem behaviors (socially offensive, destroys property, runs away, bolts or wanders or hurts self or others,)

Caregiver Ability

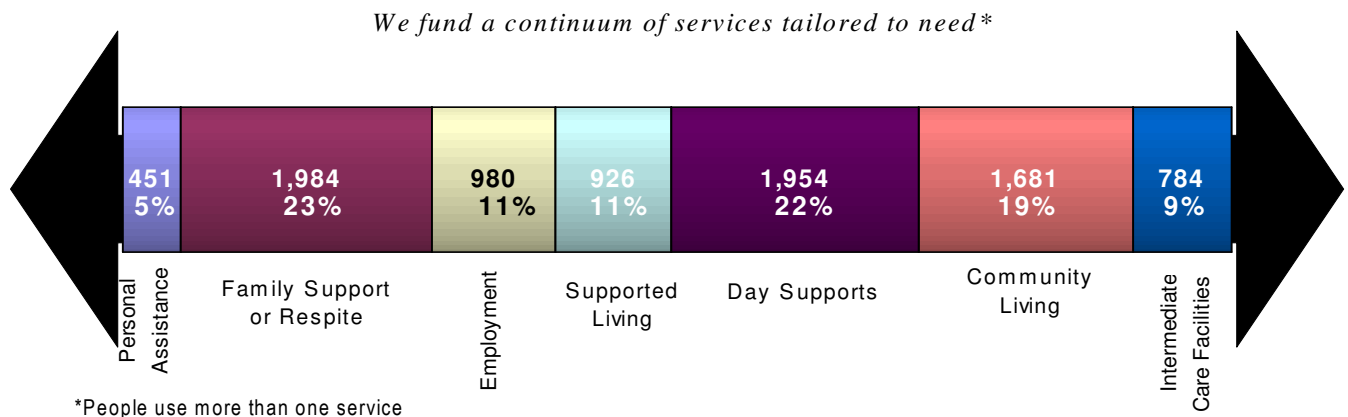
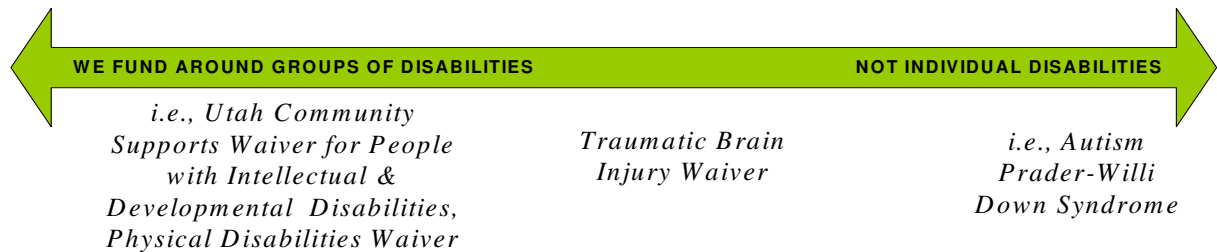
- Caregivers/households are living in poverty
- Caregivers/households have limited access to transportation
- Caregivers are the person's sole caregiver
- Caregivers who are aged, terminally ill, mentally ill, physically ill or otherwise unable to continue to care for the person
- Caregivers who have multiple people under their care

Additional Need Factors

- Must have been on the waiting list the longest
- Must have both a highly severe disability and a caregiver with limited ability to care

Over the past 10 years, only the top 5-15 percent of people waiting for services received funding for services.

What Policy Decisions Have We Already Made in Utah?



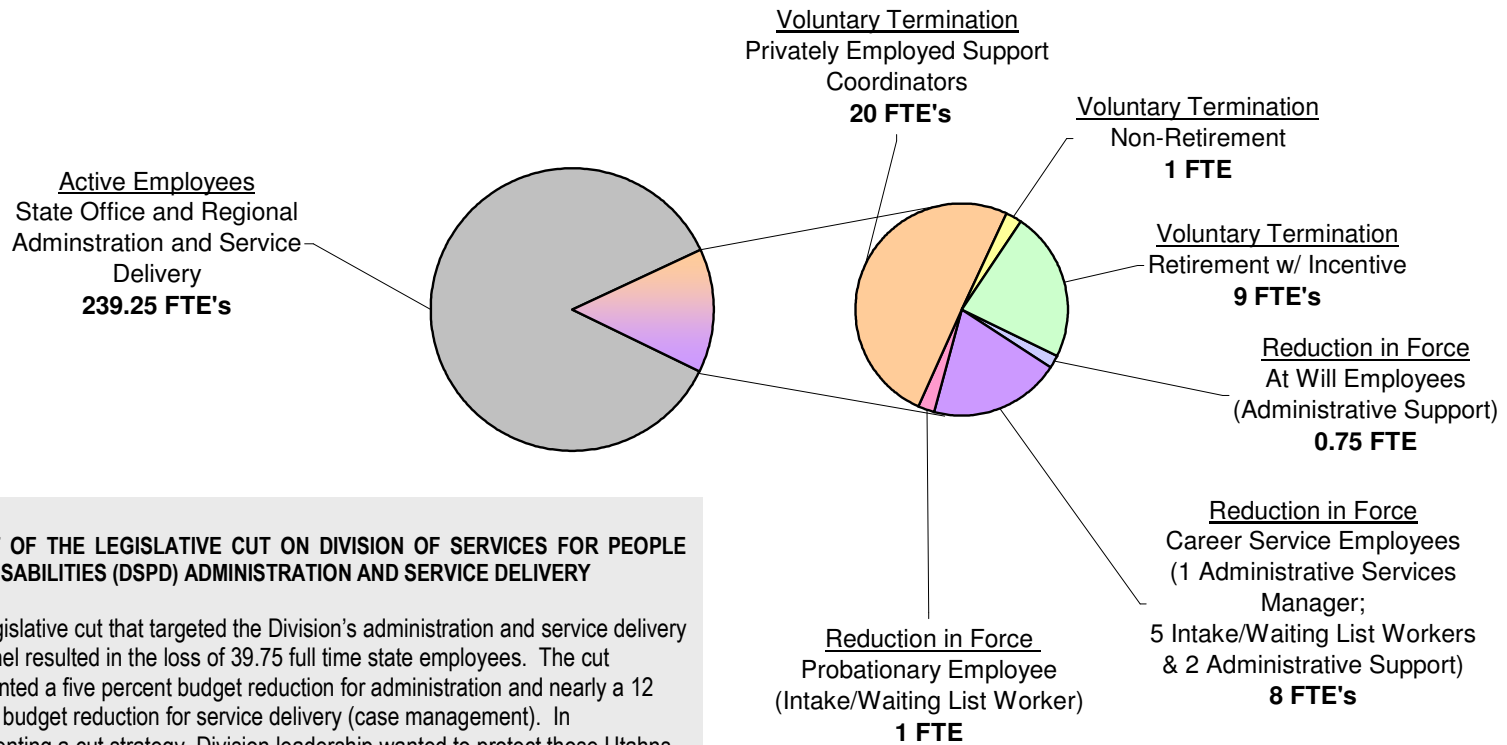
The Division uses about 90 private provider agencies to deliver services at a total annual cost of approximately \$133.3 million. Last year (FY 2009), the provider increase appropriated to private providers totaled \$3.98 million including \$1.18 million of State General funds. This year (FY 2010), private providers will be cut by \$4.67 million or 3.5 percent.

DSPD Personnel Cuts

39.75 of 279 Full Time Employees = 14% Cut to DSPD Full Time Employees

\$105,100 / \$2,093,000 = 5.0% of Administration Budget (General Funds)

\$801,900 / \$6,912,000 = 11.6% of Service Delivery Budget (General Funds)

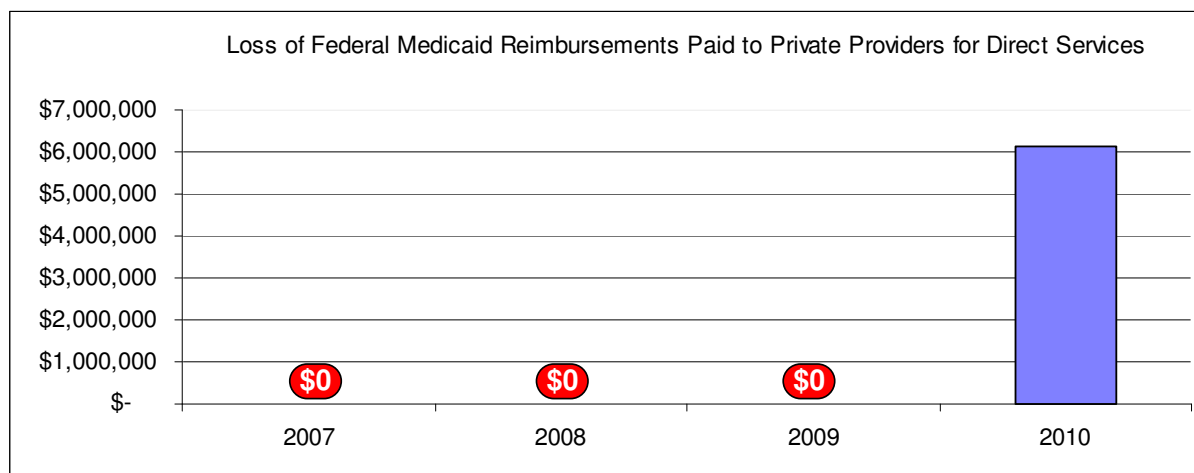


IMPACT OF THE LEGISLATIVE CUT ON DIVISION OF SERVICES FOR PEOPLE WITH DISABILITIES (DSPD) ADMINISTRATION AND SERVICE DELIVERY

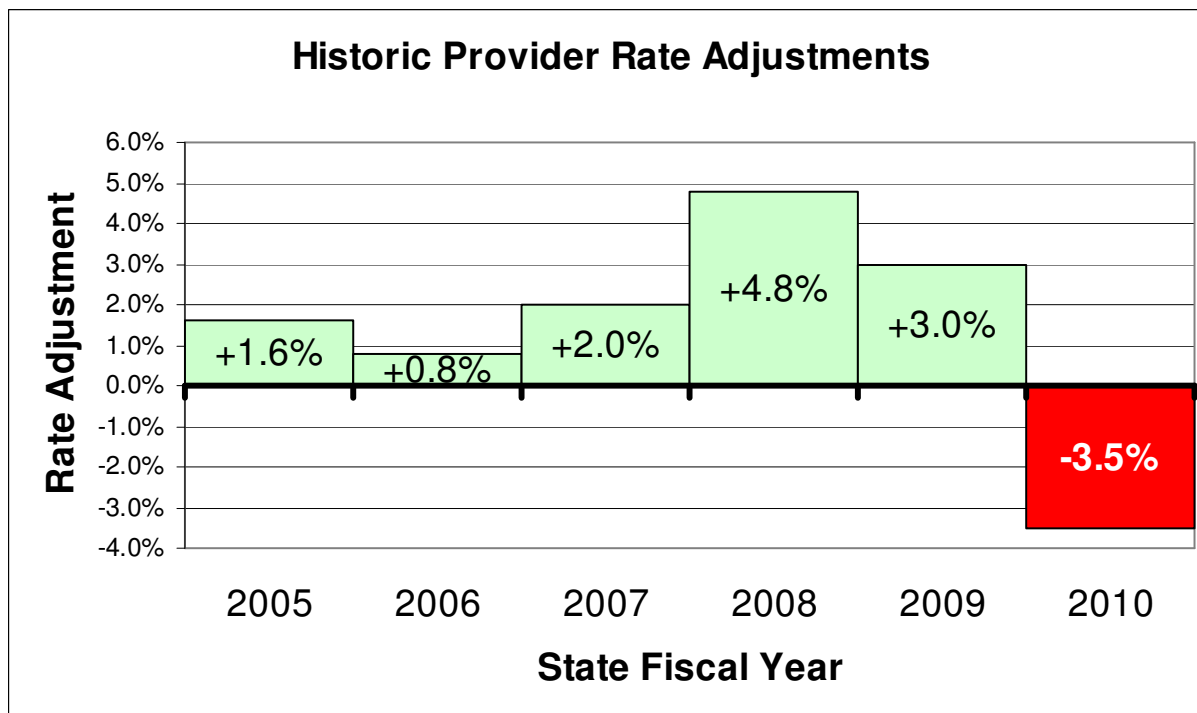
The Legislative cut that targeted the Division's administration and service delivery personnel resulted in the loss of 39.75 full time state employees. The cut represented a five percent budget reduction for administration and nearly a 12 percent budget reduction for service delivery (case management). In implementing a cut strategy, Division leadership wanted to protect those Utahns already receiving services where possible, so first Division leadership cut consultant contracts funded 100 percent with State funds so no Federal funds were lost, then encouraged employees who were thinking of privatizing or retiring to do so before finally reducing the workforce among employees receiving the lowest percentage of their wages from Federal matching funds.

What Was the Impact of the Recent Provider Rate Cut?

The Legislative cut made to private contracted providers supporting Division consumers for FY 2010 will be \$1.5 million in State General funds and \$4.67 million in total funds (General funds plus Federal Medicaid funds). This represents a decrease of 3.5 percent from the amount reimbursed to providers in last year's budget. However, due to the higher match rate in FY 2010, the total loss in Federal funds used to reimburse providers is \$6.126 million.



From FY 2005 to FY 2009, the private providers contracting with the Division to provide direct services and supports to eligible recipients of services received provider increases between 0.8 and 4.8 percent of the total budget. Beginning July 1, 2009, private providers will have service rates cut by 3.5 percent due to the Legislative budget cut.



What Is the Impact of the Recent Budget Cuts Going Forward to FY2011?

As a result of the budget cuts made by the Legislature, we are re designing disability policy in the state of Utah. We were told by the legislators to cut staff and we are doing that. We were told to leave services intact where possible--but don't add any new people in service--and we are doing that.

If disability programs get no new funding over the next two years, by FY 2011 you can expect to see the families described above have needs that increase, and Utah is legally obligated to serve them.

As a result we are doing some very specific things to cut costs:

- *Eliminating the low cost interventions that were begun over the past few years*
- *Serving no new people except court-ordered, emergency and foster children who age out*
- *Closing many offices and have fewer workers to work with families*
- *Eliminating over time, on call, certain other activities, assessments, centralize intake*
- *Cancel state fund contracts like Family to Family and Access Utah*
- *Cut provider rates by 3.5%*

Those are just the things we are doing while the cuts are partially backfilled. When the backfill runs out, the cut of \$2.7 million becomes approximately \$11 million in FY 2011 (38% additional cut). This would require us to amend one or more of our federal waivers and stop an entire set of services, such as day support or residential. Up to 1,200 Utahns could lose part or all of their disability services. We would also have to lay off an additional 105 employees, beyond the 39 we've already decreased.

As we move forward, the legislature will need to decide how best to match resources to people with needs.

What Policy Decisions Do You Want to Consider?



Here are the policy factors that the legislature needs to consider in "right-sizing" Utah's disability services:

- Number of people with disabilities that the state can serve
- Type of services to provide them (i.e., institutional v. in-home)
- Number of different services to provide them (i.e., broad variety/tailored v. one or two services)
- Number and type of state staff to provide services (caseworkers? contract monitors?)
- Balance between private providers who deliver services and state employees who deliver services
- Balance between general fund only services and services that are state/federal match money
- When you will serve people (only in acute need v. early intervention to prevent crisis)
- Degree of oversight and accountability you need to protect taxpayer investment